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Integration of cancer survivorship care and primary care practice

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More than ten years ago, the Institute of Medicine (IOM) released a seminal report: "From cancer patient to cancer survivor: lost in transition."[1] In this publication, the IOM highlighted the now more than 15 million US adults with a history of cancer[2] and outlined necessary components of high quality survivorship care. Not unexpectedly, the IOM recommendations relied on the availability of well-informed and responsive primary care survivorship providers. Yet, in the time since that report, the primary care and oncology workforce has shrunk (and will continue to do so),[3] while provider uncertainty and survivorship knowledge gaps persist.[4,5] Therefore, although oncologists, patients, and other stakeholders are looking toward a primary care context for high quality and life-sustaining survivorship care, uneven survivorship care delivery has continued. Unfortunately, failure to meet the health care needs of cancer survivors appears to result in adverse outcomes.[6]

In this issue of JAMA IM, Rubinstein and colleagues describe the results of a unique, high quality, qualitative study of survivorship care in 12 advanced primary care practices and patient-centered medical homes across the US.[7] The purposes of the study were to better understand the primary care environment for cancer survivors and to identify opportunities for improvement or enhancement.

In each included practice, the authors conducted 10–12 days of observation, provider and administrator interviews, and survivorship patient pathways. Interestingly, the authors found that none of the 12 practices had comprehensive cancer survivorship services in place. In addition, three barriers to implementing survivorship care in the primary care setting were discovered. First, providers did not identify cancer survivors as a distinct clinical category; many providers could not verbalize the components of survivorship care, beyond monitoring for recurrence. Although providers may have been performing some of the other tasks outlined by the IOM (screening for second cancers, monitoring for late effects, or coordinating care between the oncologist and the primary care settings), there was a lack of unity of purpose of these activities. Second, providers had received either limited

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information on individual patients' cancer history and recommendations, or the documentation received was not actionable. Notably, even when details of cancer diagnosis and treatment history were available (for example, in the shared medical record), the providers were often uncertain of appropriate risk-based screening guidelines; time and distance from therapy contributed to the degree of clinical uncertainty. Not surprisingly, this absence of actionable information often resulted in unaddressed survivorship care. Third, the authors found that available information systems were insufficient to support appropriate survivorship care. Without a method for identifying cancer survivors as a distinct clinical entity (the way, for example, older adults or patients on dialysis might be annotated), providers could not easily identify those who need survivorship services, or update survivorship care plans as new recommendations emerged.

It is critical to elaborate on the relevance of these findings for provider education, health care policy, and survivorship research. Rubenstein and colleagues note that providers do not identify survivors as a distinct clinical category and do not have actionable information pertaining to cancer diagnosis and treatment history. In the decade that has passed since the IOM report, educational initiatives for students, trainees, providers and patients have grown exponentially. Most notably, in 2016, the American Society of Clinical Oncology, and American Academy of Family Physicians, and the American College of Physicians introduced an annual survivorship symposium (http://survivorsym.org/) to encourage instruction and partnership among providers in primary care and subspecialty medicine. Yet, the current investigation implies that knowledge gaps remain. Primary care providers continue to struggle with how to think about cancer survivors or offer high quality survivorship care, suggesting either inadequate reach or ineffective technique of current educational initiatives and survivorship guidelines.

The health care policy implications of this work should also be highlighted. Recently, the American College of Surgeons' Commission on Cancer (CoC) criteria for survivorship care stipulated that oncology practices document the development and delivery of a treatment summary and survivorship care plan to both the patient and the primary care provider, as a quality standard. In other words, oncology providers must condense and summarize the treatment course, while outlining follow-up recommendations, in order to meet the CoC standards of quality care. Although survivorship care plans are not sufficient for primary care practices to provide high quality survivorship care, they are necessary (as emphasized by the current study). With a quality metric in place, it is logical that a survivorship care billing code should follow (which is not the case currently); provision or revision of a survivorship care plan could be one condition for reimbursement.

Finally, while the results of this work provide tremendous insight into the primary care survivorship environment, they also identify opportunities for future research. Most notably, among the 12 advanced primary care practices evaluated for this study, including 9 National Committee for Quality Assurance Level 3 patient-centered medical homes, and all with electronic medical records, insufficient current information systems remained a hindrance to survivorship care. Next steps in this work should include: building cancer diagnosis and stage into a searchable field in the medical record, developing clinical decision aids that incorporate evidence-based follow-up guidelines at the point of care, and creating communication facilitators that allow for reimbursable and expedited exchanges between primary care and oncology providers. One could imagine a scenario where a primary care provider in a community setting wonders if his patient, a breast cancer survivor, has an indication for a bone-modifying agent; the provider in that scenario should have an information-systems facilitated or medical record-based method for finding the answer to that question, either from the treating oncologist or a reliable proxy. Rubenstein and colleagues have engaged innovative and high-quality methods to produce the first step in this process: describing the current primary care environment for cancer survivors. Although there is still much that can be studied to understand the reasons for the observed breakdowns, it is not too early for testing creative and innovative approaches to enrich this care.

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